DOCUMENT RESUME

ED 456 598 EC 308 583

| | |
|---|---|
| AUTHOR | O'Brien, John |
| TITLE | Deliberate-Fire: An Account of Organizational Transformation in Onondaga Community Living, Syracuse, New York. |
| INSTITUTION | Responsive Systems Associates, Lithonia, GA. |
| SPONS AGENCY | National Inst. on Disability and Rehabilitation Research (ED/OSERS), Washington, DC.; Syracuse Univ., NY. Center on Human Policy.; Minnesota Univ., Minneapolis. Inst. on Community Integration. |
| PUB DATE | 1995-00-00 |
| NOTE | 26p. |
| CONTRACT | H133B80048 |
| AVAILABLE FROM | For full text: http://www.soeweb.syr.edu/thechp/wnew. |
| PUB TYPE | Information Analyses (070) |
| EDRS PRICE | MF01/PC02 Plus Postage. |
| DESCRIPTORS | Adults; *Community Programs; Empowerment; Group Homes; Helping Relationship; *Independent Living; *Mental Retardation; *Organizational Change; Organizations (Groups); *Program Development; *Program Evaluation |

ABSTRACT

From April 11-14, 1995, the Onondaga Community Living (OCL) organization hosted a team of five visitors sponsored by Syracuse University's Center on Human Policy. OCL provides services to empower and individually support people with developmental disabilities. In investigating the organization's move toward the provision of individual supports in integrated settings from group home placement, the visitors gathered stories of personal and organizational change from the point of view of nine of the people OCL supports though individualized services and group residences, families, housemates and assistants, and OCL staff. In this paper, the visitors reflect on the stories of change they heard and identify some implications for OCL. Recommendations are provided and fall under the following nine themes: (1) deepening understanding in order to better assist people who have a home base to move toward positive experiences and relationships and more valued roles; (2) actively helping people build community membership and friendships; (3) acknowledging the people OCL assists as they strengthen their own voices; (4) building stronger relationships with families; (5) strengthening households; (6) making the most of the gifts and learning of all staff; (7) keeping individual planning and case management in context; (8) making a distinctive contribution in employment support; and (9) keeping the OCL mission alive. (CR)

Reproductions supplied by EDRS are the best that can be made
from the original document.

ED 456 598

# DELIBERATE-FIRE: AN ACCOUNT OF ORGANIZATIONAL TRANSFORMATION IN ONONDAGA COMMUNITY LIVING SYRACUSE, NEW YORK

**John O'Brien**
**Responsive Systems Associates**
**58 Willowick Drive**
**Lithonia, GA 30038**

**1995**

This paper was supported through a subcontract from the Center on Human Policy, Syracuse University for the Research and Training Center on Community Living, University of Minnesota, supported by the U.S. Department of Education, Office of Special Education and Rehabilitative Services, National Institute on Disability and Rehabilitation Research (NIDRR), through Contract No. H133B80048. Members of the Center are encouraged to express their opinions; however, these do not necessarily represent the official position of NIDRR and no endorsement should be inferred.

U.S. DEPARTMENT OF EDUCATION
Office of Educational Research and Improvement
EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)
☑ This document has been reproduced as received from the person or organization originating it.
☐ Minor changes have been made to improve reproduction quality.
• Points of view or opinions stated in this document do not necessarily represent official OERI position or policy.

BEST COPY AVAILABLE



EC 308583

# Deliberate–Fire

## An Account of Organizational Transformation in Onondaga Community Living Syracuse, New York


*Visitors*

Kathy Hulgin  Linda Kahn  Jo Krippenstaple

Connie Lyle O'Brien  John O'Brien*


*Process*

From 11-14 April 1995 Onondaga Community Living (OCL) hosted a team of five visitors, invited by OCL's board and staff and sponsored by Syracuse University's Center on Human Policy. At the OCL board's request, the visitors gathered stories of personal and organizational change from the point of view of nine of the people OCL supports through individualized services (7) and group residences (2), members of their families, their housemates and assistants, OCL staff, and present and former board members. Joined by Bob Lehr, a board member, Pat Fratangelo, OCL Executive Director, and Beth Corrice, OCL Program Coordinator, the visitors reflected on the stories of change they had heard and identified some implications for OCL. Before leaving, visitors discussed their reflections with OCL board and staff and with a group of people from outside OCL who are involved in its development.

---


* Report writer.


Preparation of this paper was partially supported through a subcontract to Responsive Systems associates from the Center on Human Policy, Syracuse University for the Research and Training Center on Community Living. The Research and Training Center on Community Living is supported through a cooperative agreement (number H133B80048) between the National Institute on Disability & Rehabilitation Research (NIDRR) and the University of Minnesota Institute on Community Integration. Members of the Center are encouraged to express their opinions; these do not necessarily represent the official position of NIDRR.





BEST COPY AVAILABLE

This report's title, Deliberate–Fire, came up as the visitors talked about the challenges arising from OCL's succeeding more rapidly than its leaders had planned. OCL has created effective individualized supports for people by carefully considering opportunities to realize its values for one person at a time. This deliberate process has generated growing commitment to a new mission, new capacities, new skills, and new expectations. Like fire, this commitment changes what it touches irreversibly, and in ways that are difficult and a bit dangerous to control. OCL's methodical demonstration of its ability to act on what its staff hear from the people they assist has fired the imagination of more and more of the people and families OCL serves. They see other people living with individual support and they want similar changes for themselves. Reasonable demands, that accelerate faster than the agency's capacity to deal with them, call for a new kind of learning: learning how to more rapidly invest agency resources in its best practices. If deliberateness dampens the fire sparked by board and staff commitment to OCL's mission, the agency's spirit is at risk. If fire consumes the agencies ability to take thoughtful steps, OCL's capacity to act for people is impaired. The next chapter in OCL's development will be strongly influenced by its leaders' ability to handle deliberate–fire.

### OCL's history and mission

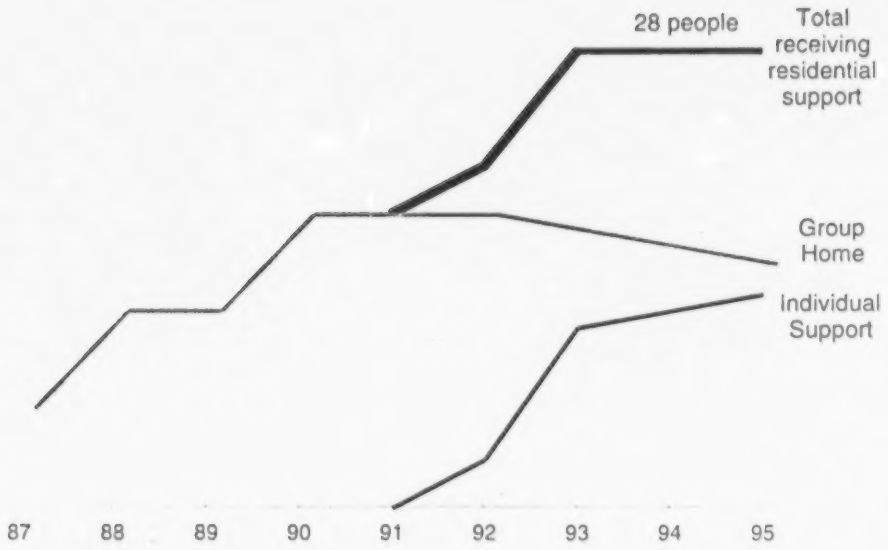
OCL is one of a growing number of agencies committed to closely matching the assistance it provides to individual circumstances in order to increase opportunities for people with developmental disabilities to experience the benefits of community life. OCL's mission, adopted in January 1993 after extensive discussion, expresses this commitment clearly.

> *Onondaga Community Living's Mission is to empower and individually support people with developmental disabilities in their efforts to live full lives as integral, respected members of the community.*
>
> *We achieve this by:*
>
> *1) Listening to and focusing on each individual.*
>
> *2) Helping each individual build positive relationships with others.*
>
> *3) Supporting each individual's effort to achieve personal fulfillment.*
>
> *4) Exploring and developing ways to support each individual in his or her personal pursuits.*

OCL's mission refines values that have been present since the agency's founding in terms of its more recent experience of providing individualized support services. Since 1984, when local families began to organize to assure effective residential services for their sons and daughters, OCL has valued ...

- Respect for the dignity and worth of each person with a developmental disability.
- Recognition of the vital role of families in assuring that supports are of good quality.
- A desire to offer people with disabilities state of the art services.
- A willingness to be assertive in relationship to OMRDD and its local office. This assertiveness was expressed early when its founders successfully insisted that OCL group homes would house no more than six people. It has led OCL leaders to cultivate strong, direct personal connections both with the local DDSO and with OMRDD's central office.
- The choice to be small in overall scale so that all the people involved with OCL could be known to one another personally. Currently, board members and staff informally agree that OCL should provide residential support to "about 30" people.
- A strong relationship with the Center on Human Policy. Bernice Schultz, the organizer of the parents who founded OCL was employed by the Center on Human Policy at the time; the current visit was sponsored by the Center in response to OCL's request.
- Making public what OCL learns about supporting people with disabilities and their families.
- Working actively to influence local and state policies and practices.

In the first half of its history, OCL realized these values by establishing and operating three small group homes. In 1991-92, OCL began to offer individualized support to people who were newly referred to OCL. In 1993-94, OCL began to provide individualized supports to people moving out of group homes, and in 1994 the OCL board decided to fund all of its supports under the HCB waiver program, reduce the number of people served in group homes, and to move toward closing one group home. (The figure below describes OCL's pattern of growth.)




**New capacities and new problems**

As its ability to shape and implement individualized plans with people has grown, OCL has developed new capacities, new understanding, and new problems:

- Board and staff members have a growing appreciation for the benefits of individualized supports and a sense of confidence that OCL can solve the problems of assisting people "one person at a time." It seems clear to most of them that the OCL mission points to individualized services.
- Board and staff members have a deepening sense of the limitations imposed by the design and logic of their group homes. More and more staff believe that they would be better able to support people individually.

  *"We used to be able to tell people that the reason they can't have their own place was because they hadn't learned the skills they needed to move on. Now we know that's not true."*

- OCL has served as an effective medium for growing supports initiated by people outside OCL who have a clear idea of what is necessary and need specific assistance to make it work. Both parents of people with disabilities and staff from Seguin Community Services have entered this sort of partnership with OCL.
- The planned closure of Oak Hollow, which began in response to the expressed desire of three resident's to move, has shown the effectiveness

---

* Quotes are from the group's discussions and include quotes visitors read from their interview notes.

with which staff have learned to plan with people and their families. Careful listening, over time, to personal and family aspirations, fears, and concerns, combined with creative problem solving, has lead to feasible individual support plans for all of the residents of Oak Hollow, including three women who did not request a move before the process of exploring the future with them began. Recognizing this capacity means reconsidering two assumptions: a) that the group home is "right" for some people and not for others and b) that OCL's role is to wait until a person or a person's family clearly says that he or she wants a change: OCL staff now know that they can make a substantial positive difference in the confidence people and their families have to see and work on new possibilities.

- Board and staff members have benefited from a number of educational opportunities which have helped them see the links between their work and the work of innovators in supported living and housing. This continuing educational process accelerates their desire for significant change.
- OCL staff, and some family members, demonstrate great skill and tenacity in actively negotiating people's plans with local and state officials.
- OCL staff have learned how to make use of the most flexible funding sources currently available from OMRDD (HCB waiver funds and ISS funds).
- OCL, and some families, have become skilled in recruiting housemates for people with disabilities. Often housemates live with people with disabilities in exchange for free rent rather than for cash payments.
- A number of OCL staff have chosen to share their home life with people OCL supports without additional money compensation.
- OCL has successfully negotiated a plan to close one group home with OMRDD. Board and staff are now developing the way to sell the group home.
- It no longer makes sense to fill vacant places in group homes with new people. Given the strong local priority on moving people out of the Syracuse Developmental Center, local OMRDD administrators could view this as a loss of needed "beds" and a failure to support deinstitutionalization efforts.
- Demand for individualized services from people OCL serves in group homes grew very slowly for three years. In 1991 all of the families declined an invitation to plan for individualized services. But, after growing very little for three years, demand has more than doubled in the past few months. Now, in addition to the people OCL plans to move from the group home already scheduled to close, people in each of the other group homes have specifically requested help to move. OCL's inability to respond to these requests in a timely way creates a conflict for at least two families: should

they support the desire to move and create a problem for OCL, or should they support OCL's deliberate pace of change and delay their son or daughter in taking an important step in their lives.

*"I want to move out, but I'm waiting behind the people from Oak Hollow."*

### Three dilemmas call for new learning

These developments create three dilemmas, which can be paraphrased like this...

- "If we believe that individual support is better for people than group home living, and if we have the ability to work with people and their families in a way that is likely to result in a more individualized service arrangement, it seems inconsistent with our mission to only respond to the most vocal people. We should be working to extend everyone's possibilities, but that means making some people wait for us to catch up."
- "The rationale for the group homes has been lost. As long as unresolved organizational issues (such as maintaining occupancy to pay mortgages) are a significant reason we are not planning with people we won't be living up to our mission. Life in the group home begins to seem like 'life on hold.'"
- "We have made positive changes by focusing on one person at a time, but that was easier to do when we were dealing with one external referral at a time than it is when we turn to the people living in our group homes. The people in our group homes are individuals who are so tightly linked to the other people who live with them that we can only respond to them as individuals by dealing creatively with the group. One person's move could affect the financial balance of the whole agency. The obvious alternatives –moving new people into "empty beds" or continually moving people from one home to another to keep them one of a changing group– don't fit our values."

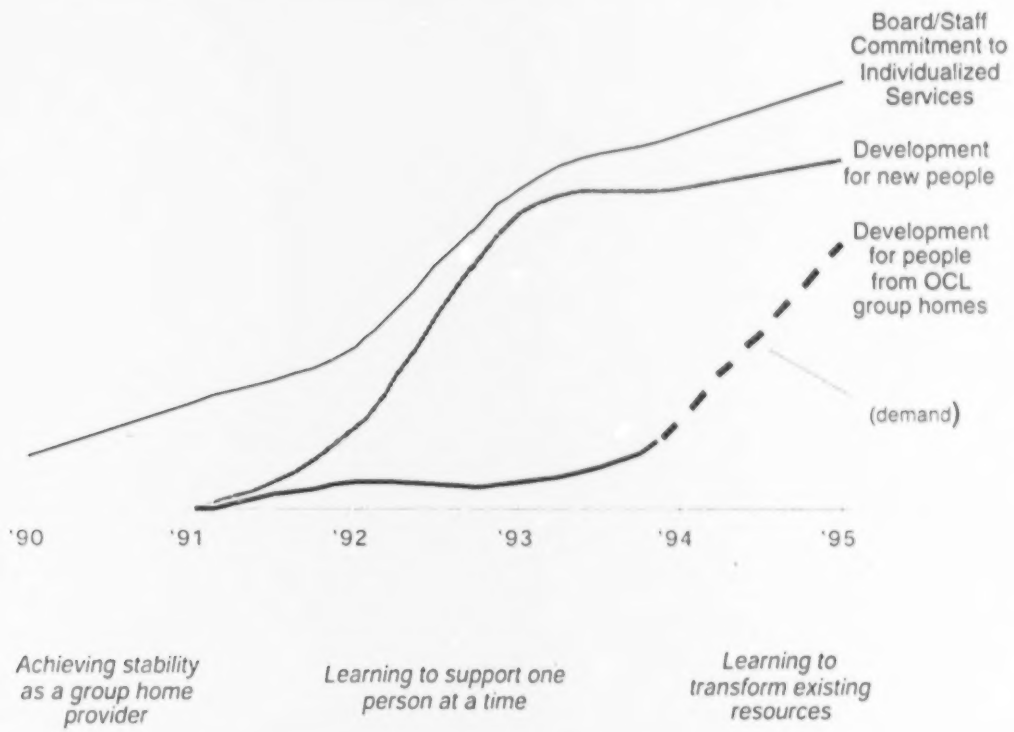
Dealing effectively with these dilemmas calls for OCL to enter a new chapter in its development.

The diagram below provides a context for each chapter of OCL's learning. While achieving financial and programmatic stability (Chapter 1), OCL began to successfully develop individualized supports for people from outside the agency (Chapter 2). Success in this work, and sustained educational activities, increased board and staff commitment to individualized services. Then, after a delay of almost two years, these positive influences have rippled out, and demand from people now living in group homes is growing rapidly (Chapter 3).

In the first chapter, the organization's learning task was to become stable and solvent as a group home provider. In the second chapter, which is just closing, OCL's primary learning task has been to support people one person at a time.

The current chapter, which is just opening, calls for transformation of existing resources to allow each person well planned individual supports.

Of course, the lessons of previous chapters remain to be learned and re-learned. The need to transform existing resources doesn't take away the need to remain solvent or the need to continually improve ability to provide individual supports. But meeting the challenge of increasing demand from people OCL is already committed to puts both of these tasks in a new context.




The slogan for this new chapter is, "More is different." Until very recently, there was little desire for individualized services from among group home residents. In a sense, the process of development was controlled by the shortage of people and families who wanted to move from a group home. Lack of demand from people within OCL freed staff to respond to new people at a pace they could control by deciding when to accept referrals. Now desire is growing rapidly among people, family members, and staff in the group homes .

It is tempting to deny that "more is different," and there are at least two ways to do so. One is to remind people, as staff of many facilities must remind people every day, that life is unfair and that people will be served as soon as staff can get to them. No matter how gently delivered, this reminder has a much different significance among a small group who aspire to believe in one another and support one another in pursuing their dreams than it does in a larger, more bureaucratic agency. The second is to wish for control of people's aspirations

and dreams. Asking staff not to encourage people in group homes to talk about their dreams for fear that such discussion will make people "crazy" expresses such a wish.

Denial is costly. People with disabilities may conclude that they have to be silent about what matters to them in order to keep down staff anxiety. Family members may feel that they must decide whether OCL can provide the kind of support necessary without the active involvement of OCL staff. Staff may give in to the temptations of cynicism and depression about the contradictions between mission and practice.

Denial is unnecessary. Most of the people associated with OCL –people with disabilities, family members, board, staff, and outside supporters– believe in its mission, have justified confidence in the achievements they have already made, and care about one another. What is needed is clear ways for people to work together to transform existing resources to new, more individualized uses.

Obviously we have no plan to offer OCL, but we will outline three possible steps for discussion and amendment by OCL's board. It is important to note that these are the visitors conclusions and ideas, based on their interviews.

**First,** develop a public statement on OCL's mission which clearly states that OCL intends to move to the provision of individual supports as soon as specifically stated conditions are met and that OCL does not believe that the operation of group homes is consistent with its mission.

> *"We need to bring people together to explore the 'waiting list' perception... and to look for many more ideas for ' quick and creative closure.'"*

- This statement may cause some concern among the families of people now living in group homes, so it needs to be developed in cooperation with them. In considering the future of people now in group homes, at least three considerations seem important...

  ...OCL's commitment is to collaborate with people and their families to deliberately and carefully develop individualized supports.

  ...Individualized supports are not the same as people living alone. It is interesting that even some of the family members of people who live with several non-disabled housemates say that the person lives "alone," so this point will take some discussion.

  ...The fact that current households are organized around one person with a disability does not mean that people with disabilities who want to live together would be forbidden to do so. Individualized support plans might include supporting two people with disabilities who want to live together.

- This direction is of considerable interest to leaders of the local DDSO, so they should be informally involved in its development as much as they are able to be.

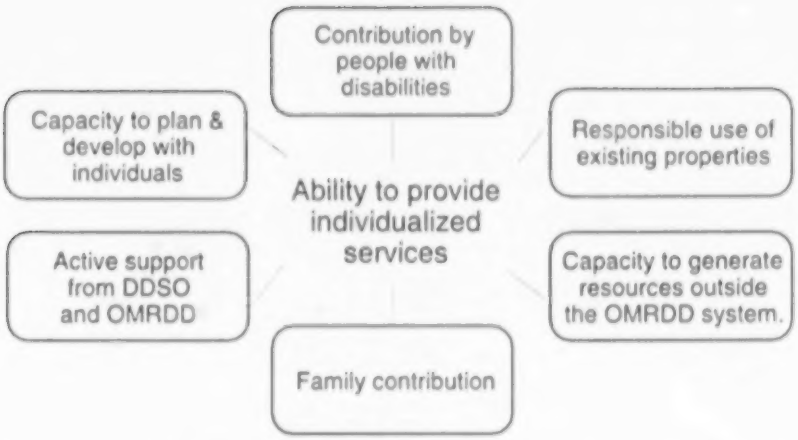
  ...Because the pace of change is more rapid than OCL could have predicted, and because OMRDD structure and policy are currently turbulent, OCL must make special effort to insure that its allies in the OMRDD system have no reason to interpret OCL's increasing pace of change as a reason for mistrust.

  ...There may well be important issues of disagreement to negotiate over how OCL can best contribute to local development given the mismatch between a high local priority on deinstitutionalization and OCL's current internal focus. This potential conflict should be thoroughly discussed informally between DDSO leadership and interested OCL board and staff members.

**Second,** identify the key resources required to provide individualized supports for all of the people OCL is committed to serving and organize ways to further develop each resource. The diagram below represents a rough draft which identifies at least six key resources.

Developing these resources requires thought as well as action. People need to identify and re-think some of the assumptions that have worked to get OCL to where it is now. For illustration, we will sketch some preliminary ideas related to four of these key resources. In this discussion, we have stated the assumptions very flatly. Though we have drawn them from what we heard from among the people we interviewed, we don't think that everybody holds these assumptions and certainly people would not state them as baldly as we have. Indeed, if people look at our statements about assumptions and say, "We don't believe that!" they will have served an important purpose.

> *"We need to look beyond OMRDD for support; we can't just rely on them. We have to use our own imagination to reorganize our resources and generate new ones. Don't get trapped in 'we can't do it now because..."*


Contribution by people with disabilities
Capacity to plan & develop with individuals
Responsible use of existing properties
Ability to provide individualized services
Active support from DDSO and OMRDD
Capacity to generate resources outside the OMRDD system.
Family contribution

- People with disabilities can make substantial contributions if they have opportunities to understand and think about and participate actively in improving the situation that faces OCL. Further developing this resource may challenge these possible assumptions...

  ...that family members voices and efforts make a contribution which can substitute for the voices and efforts of the people OCL serves.

  ...that people with disabilities whose lives and futures are economically intertwined can be approached as if they were separate individuals with no ties or obligations to one another, i.e. that people with disabilities are simply 'customers' and OCL is simply a kind of store that either has what people want in stock or loses their business.

  ...that people with disabilities can't understand, or shouldn't have to understand, issues that shape the future of an agency that they rely on.

  ...that people with disabilities can't, or shouldn't have to, work hard in collaboration with other people to make important changes in their lives; it is OCL's primary responsibility to make people's wishes come true.

  Potential resources include: Center on Human Policy staff experienced with self-advocacy and members of Self-Advocates of Central New York .

- Many families can make a significant difference in the resources available to the people OCL supports. OCL families are now actively involved in locating or providing housing; hiring, training, and supervising people who assist; designing and re-designing support systems; and developing resources. Family to family exchanges about what people have learned about planning, homes, supports and dreams might extend these resources. Further developing this resource may challenge these possible assumptions...

  ...that family efforts will get in the way of OCL staff doing their jobs

...that the only way a family can contribute is with cash

...that parents are the only family members who can contribute

...family members can only speak for or support members of their own families (instead of for example, 'adopting' someone whose family is unable to support them)

...that once a person is 'placed' with OCL the family's primary role is to monitor OCL's performance

...that families whose situations are economically intertwined by their common involvement with OCL can be treated solely as individuals instead of as individuals who are part of a common effort.

...that OMRDD should assume complete responsibility for people with developmental disabilities

Potential resources include: Families involved with the Midland, MI ARC; families who belong to Movin' Out in Dane CO, WI, and families who have founded New Frontiers in London, ON.

- Making responsible use of OCL's three properties means carefully considering the way to realize the greatest long term benefit from all of the properties. It may be that selling properties one by one and using any profit to cover non-recurring expenses related to people's moves is the best option. But given that holding these properties is one of the biggest constraints on developing individualized services, it may be worth expanding the range of options for best use of all three unnecessary properties.

  Potential resources include: Jay Klein ( National Home of You Own Initiative); Ann Mitchell ( David Reece Fund) and Marcie Brost (WI Bureau of Developmental Disabilities).

- Capacity to plan and develop with individuals is perhaps the most fundamental resource. Without systematic, sensitive, sustained and creative ways to engage people, their families, and their allies in surfacing fears and hopes and making and implementing plans together the rest of the resources lose their focus. This process may move more surely as resource people gain experience, but it probably can't be made to go much faster, especially when the focus is on people and families who are re-assessing past decisions about the best living arrangements. Expanding the effectiveness of this resource means more than building skills, it also means mentoring people to listen deeply, and negotiate conflicts creatively, and solve problems imaginatively.

  - There may be people who are not OCL staff who would be able to share the work of planning and making changes.

- As we discuss below, everyone OCL supports, regardless of where they live, should have the opportunity to thoughtfully consider what would make their life better and safer.
- Anyone who lives in a group home who expresses interest in moving should have the opportunity to begin the planning process with OCL support. People involved in this process will face different constraints and opportunities (e.g. some people may need to move faster to deal with a group home closure; some people may have to address the impact of their decisions on others they live with) and the process will move at different paces, but no one's dream of their own home should be placed on hold or discouraged. Staff and board must practice the discipline of encouraging creativity when what a person wants is delayed through no fault of the person's.
- The demand for figuring and preparing multiple versions of individual budgets may mean that limited bookkeeper time creates a bottleneck in the process. Transition may call for more bookkeeper time and for ways to teach other OCL staff to prepare trial individual budgets.

**Third,** acknowledge the dilemmas, contradictions, and scarcities that shape the present moment and ask for support. This effort needs to combine group discussions and individual conversations. For people and families who experience themselves as waiting, this conversation and request needs to be made person-to-person, not by mail, or indirectly, or in a group setting, or by waiting until a potential crisis forces the conversation.

### Themes for continual improvement

As OCL learns to assist each person to have a secure home base, respectful and capable household companions, and a sensible daily routine, the opportunities begin for real learning about how to assist people "to live full lives as integral, respected members of the community." We believe that this learning will engage at least these nine themes:

- Deepening understanding in order to better assist people who have a home base to move toward positive experiences and relationships and more valued roles
- Actively helping people build community membership and friendships
- Acknowledging the people OCL assists as they strengthen their own voices
- Building even stronger relationships with families
- Strengthening households
- Making the most of the gifts and learning of all staff
- Keeping individual planning and case management in context

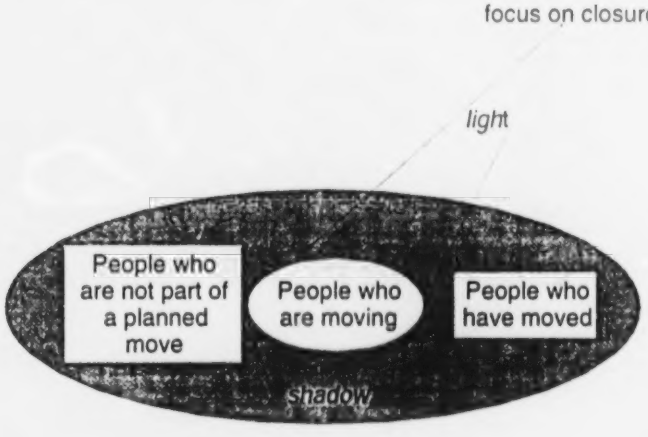
- Making a distinctive contribution in employment support
- Keeping the OCL mission alive

We explore each of these themes for continual improvement in turn. For each theme we identify a possible problem scenario. This possible problem scenario plays out *what* could happen *if* possibilities we observed in the present were to develop unchecked. This scenario is not a prediction or a curse, it is just a way to describe the theme by describing some of the possible consequences of ignoring it. Then we identify a set of opportunities. These opportunities are not so much recommendations for OCL to implement as they are indications of the kinds of action implied by the theme. We believe that people at OCL will be able to come up with many more ways do deal with these issues when they set their minds to them.

### Deepening understanding in order to better assist people who have a home base to move toward positive experiences and relationships and more valued roles

Possible Problem Scenario

The process of moving people into their own homes absorbs most of OCL's attention. Once people have a secure home, those OCL staff with the greatest gift for planning with people focus on the next person who wants to move, refocusing their attention only if a person's living arrangement becomes unstable or if the person is identified as having a problem or an 'issue'.




*"I like my life, but I want to be somebody."*

*"Capturing imagination is important, not just around the move, but around all the little things that can make life happy... Don't forget to slow down and look at the minutes and days...."*



BEST COPY AVAILABLE

*"...'closure' is not our goal; our goal is offering the individualized services that will allow people to create better lives."*

*"Find 100 ways to say and show planning means more than planning for moves or talking about people's problems."*

*"We need to work as hard during the good times as we do during the hard times."*

Opportunities

- Assure that, once people have moved into their homes and developed an acceptable at home routine, each person has opportunity and encouragement to consider ways to increase desirable experiences, relationships, and roles. This process should include other people who are or can be resources to the person.
- Keep asking, "What isn't happening yet?" in a person's life. This question provides a safeguard against diminished expectations or complacence.
- Be sure that some of the time in regular staff discussions is spent thinking about (small) improvements in people's 'now' and not just in discussion of big changes or difficult issues. This process often involves disrupting routine perceptions of a person by stopping to listen to what a person "always says but never does anything about" or what everyone 'knows' is 'unrealistic.' Sometimes gathering up what people say and presenting it back to them for their further consideration helps a person clarify what's next. This example comes from a letter one of the visitors sent to a person she interviewed:

  *"I was really struck when you said, 'I like my life, but I want to be somebody. I feel like I am wanted, but I still want to prove to other people (my family and others) that they are all wrong about me not being able to do things.' You said you have good dreams about yourself, but other people don't believe in those dreams. The good dreams you have about yourself include.... going to school to learn to cook better, having some kind of involvement with a real restaurant instead of being a dishwasher in a nursing home, learning to read, trying to get a driver's license, finding a woman who likes you and would like to do things with you, having friends who invite you to do things with them and who call you on the phone.... You'd like to have some of the same things in your life that the people you know and care about have in theirs. You have a good house and you like it. You have a brother and sister who care about you (even though you don't always agree with them about what is best for you) and a housemate that you like, but those things are not*

*enough. You want to be SOMEBODY. You are somebody to yourself, but you don't feel like you are somebody to others except to kids in the little league, some of whom are the children of the children you coached 20 years ago."*

- Recognize that, as people gain a new sense of what is possible for themselves, they may need support to mourn as well as to celebrate or problem solve. Even very positive changes involve loss, and many people will feel the effects of many years of missed opportunities due to low expectations even more acutely when things begin to change for the better.
- Increase OCL's capacity for assisting people to plan by encouraging capable staff to develop their skills through...

  ...at least every other month group reviews of "what we are learning about planning with people" hosted by involved OCL staff and open to experienced others

  ...individual plans for those interested in developing and improving their ability to plan with people, including: participation in training in person centered planning, group facilitation, and creative problem solving; systematic coaching by more experienced planners; and activities which will deepen the ability to listen such as assisting people to compile autobiographies, meditative review of people's service histories, and review of family experiences with people's parents and their brothers and sisters.

  ...exploration of developing planning skills, especially skills around assisting people to plan a move, among experienced family members and people OCL supports, as well as among the local network of people outside OCL who are committed to positive changes for people with disabilities.

### Actively helping people build community membership and friendships

Possible Problem Scenario

Good relationships between the people OCL assists, OCL staff and housemates, in a schedule of routine activities, diverts attention from the sustained work necessary to assist people to develop memberships and friendships.

Opportunities

- Make sure that each person has at least one other person in their life who takes responsibility for creating opportunities for memberships and friendships.

- Provide regular times for responsible people to identify what they are learning about developing memberships and friendships and to share in problems solving.
- Assure that all OCL staff and housemates have opportunities –through retreats, training, and mentoring– to deepen their understanding of the practical implications of social role valorization theory, particularly...

  ...the pervasiveness of social devaluation of people with disabilities and its wounding effects: people who are devalued (and often those who care for them) simply don't imagine the possibility of belonging to their community in valued roles

  ...that efforts to overcome long standing patterns of segregation will often be difficult, tiring, discouraging, frustrating, and even frightening; therefore, people will need active encouragement and support

  ...that expectations matter a great deal

  ...that there is a powerful tendency to blame the victim of segregation, often expressed in subtle ways: "they prefer to be with the special few people who really understand them" or "they choose not to become involved" or "it would be 'unnatural' to actively encourage memberships and friendships."
- Build staff and housemate capacity to connect people by explicitly focusing on the many small arts and graces of...

  ...introducing people

  ...offering hospitality

  ...finding connections among people

  ...pulling acquaintances closer

  ...helping people to discover their meaning to each other
- Regularly practice "thinking connections." This is particularly important in framing problem situations. For example, when a person expresses anger at the fact that a housemate gets many phone calls from friends, staff who are 'thinking connections' notice the tendency to interpret this as a personal problem ("The person is jealous.") and work to re-define the situation, "What steps can we take with the person to increase the number of phone calls the person gets."
- Keep conscious of the tendency for housemates and staff to create well intentioned barriers between themselves and others who might want to get to know the person. Such barriers could include communicating that the person's 'relationship vacancies' are filled, by them; assuming that others can't understand the person as well as they can; overlooking and failing to

encourage the small beginnings of new relationships; or interpreting some people's initial clumsiness at approaching a person with a disability as a necessary sign that the person is not suitable.

- "Thinking connections" is essential to the work of OCL supported employment staff. Creating strategies to increase employer, supervisor, and co-worker responsibility for each person's job success needs to be at the heart of their contribution.
- Part of 'thinking connections' is assisting people to organize and amplify their interests in civic affairs. The following example arose from a conversation between two visitors and one of the people OCL supports. After they checked their understanding of what he had told them, he asked that they type up his comments. Later, he said that he wanted President Clinton to know about his concerns.

*My message to President Bill Clinton*

*My 36 years of life have been very difficult. When I was little, I was placed into foster care along with my brothers and sisters. Even though my family mistreated me, I still love them. Although it probably will not happen, and it might not even be good if it did, I want to be with my family. I go back and forth with this a lot.*

*My life has been chaotic. After being placed in foster care, the rest of my life until 1992 was one move after another, from place to place that did not understand me, did not want me, believed I was dangerous and incorrigible. I guess I believed I was that way, too, and lived up to those expectations. My life changed in a big way in August of 1992 when I met some people who knew my bad reputation, but also came to know me in a different way and decided to focus on me as a person instead of as a reputation.*

*I was in a forensic unit at a state institution when I was introduced to Karen, a psychologist at Seguin Community Services, who joined with me to think about a better future for my life. Karen, who has become my friend as well as officially being my case manager, worked and planned with me to figure out a way I could live in the community instead of in a "service". Since 1992, I have gone from being a "dangerous forensic unit patient", to living in my rented home with three other guys (none of them are "clients" of the service system). We share the house. Even though my own life is delicately balanced and goes one day at a time, I am proud of what I have been able to accomplish. I now am a housemate, an employee, a taxpayer, a friend.*

*Two of my housemates get paid to live with me and help me get on with my life. Phil is paid through the Family Care Program at Seguin and Joe is paid by OCL. The third person, Richard, used to work with me, but now lives with me just as a housemate and gets no money to live with me or spend time with me. He is my housemate and friend because he cares about me and what happens to me.*

*Moving out of institutions did not end all my problems, it just put them in a different context. My housemates and me still have our struggles trying to learn how to live together, and some days are very challenging for each of us in different ways. There are days when my old reputation seems to overtake me and I do things that irritate or scare other people. I still get angry, but I am struggling to learn better ways to express it. Sometimes I succeed, sometimes I don't. But now I do have a life and even now have the energy and interest in speaking out for other people and not just for myself.*

*Karen also connected me up to a job with help from a supported employment program. Because of her, I now have a good job at Peter's, a local grocery store. I started out bagging groceries, now I stock frozen foods and help out with bagging when they really need an extra hand. I received the "Supported Employee of the Year Award" given by Onondaga County. I am proud of my job, I am proud of my store. I make enough money now that I no longer get SSI.*

*I am very worried about what is going on with my personal budget and with the federal budget. I know people are concerned about paying taxes. I am, too. It bothers me when I look at my check and see how much money comes out of it before it gets to me. Sometimes I feel like I am being punished for working. When I started working and earning money, I watched my SSI go down and down and finally away. I could be proud of not being on welfare, but then I noticed my pay check going down and down, too, with what gets taken out. I have a job. I work hard. I no longer get a check from the government, but I'm still poor.*

*I am worried and angry about cuts in the federal budget that will take away what many people need to live a decent life. I look around me and see many things that will no longer be available if the cuts continue. And turning it over to the states won't help those of us who are not seen as valuable in the eyes of either our state or our local communities.*

*Did you know that Governor Potaki is planning to drastically reduce or even eliminate the number of hours of support that*

*people like me can have, and that he has stopped the effort to move people out of the institutions. His proposal would reduce the maximum amount of support that any one person can receive to 3-5 hours/day. It will also sentence people to live the rest of their lives in institutions instead of having the opportunity like I have had to get a life.*

*As I look around me in my neighborhood I see streets and sidewalks with potholes and cracks that make it hard for anyone, much less people who use wheelchairs or have difficulty walking, to use them safely. I see people cutting down the trees and destroying the beauty of my neighborhood. I hear gunshots going off, and I am afraid. Not just for myself, but for everyone.*

*Please let me know that you've heard me. I want to work to help make things better in my neighborhood, my community and my country. If I am to do this, I need support like I get from OCL, Seguin, Supported Employment and my friends. Don't let people convince you that this support is trivial. It makes all the difference in the world. I may need help and support, but I want to help and support myself and others too.*

### Acknowledging the people OCL assists as they strengthen their own voices

Possible Problem Scenario

The great strength of OCL's roots in responding to the voices of parents reduces OCL's ability to also acknowledge the emerging, often distinct, and occasionally conflicting voices of people with disabilities themselves. This increases the risk that OCL staff will unthinkingly act as if they were stand-ins for people's parents or equally unthinkingly join the person in rebellion against parental authority.

Opportunities

- Offer parents and brothers and sisters opportunities to talk with one another about the changes in the lives of the people OCL supports and the implications of those changes for their own relationships.
- Encourage interested people with disabilities to participate in OCL agency planning, committee work, and problem solving activities.
- Develop the supports necessary to allow one or more of the people OCL assists to fill the role of board member.
- Explore ways that Self-Advocates of CNY can play a positive role in OCL's development.

## Building even stronger relationships with families

Possible Problem Scenario

From time to time, OCL will experience prolonged conflict with a family. If this conflict seems to OCL staff like a distraction from helping other people and their families move or deal with issues of higher priority to staff, the conflict can undermine the support a person needs.

Opportunities

- Aspire to bring the same level of empathy to understanding the history and situation of family members who challenge staff skills and tolerance as OCL staff are learning to bring to people with disabilities whose behaviors are persistently difficult.
- Identify people committed to the OCL mission, within and outside OCL, to act as mediators in recurrent or prolonged conflicts. Be sure that family members know that they can ask for mediation. Acknowledge that both staff and family members can become emotionally entangled in a conflict and that both parties will occasionally need help to get unstuck. Begin with the staff-family conflicts now known to the agency.
- Notice the tendency to focus on differences between family and staff (e.g. staff feeling that they believe in people while families are overprotective or family members feeling that only they can know the difficulties of living with a person while staff cannot really care). Counter this tendency by attending to ways that people are alike in their concerns for people with disabilities and commit to trying to understanding others concerns as if they were ones own.

## Strengthening households

Possible Problem Scenario

As OCL resources are stretched tighter, reliance on people's housemates to assure the quality of everyday life grows. The desire for people to experience 'natural' relationships leads to a hands-off attitude on the part of OCL staff. This desire to avoid interference is even stronger when voluntary housemates are also OCL staff members. In some situations this results in the household becoming stable around low expectations of and on behalf of the person OCL assists. When there are difficulties, this hands-off posture leaves some housemates unsupported and doing what they think best in situations where they are themselves emotionally entangled. Housemates leave abruptly, feeling disappointed or guilty and retain limited if any contact with the person OCL assists.

Opportunities

- Ask a group of housemates to meet with coordinators to brainstorm a variety of respectful ways that OCL staff can understand household

interactions and support households effectively. There will not be a single way; the goal should be to develop and try dozens of different ways.

- Regularly invite housemates, including housemates who are OCL staff, to discuss what they are learning about life sharing: the rewards and the dilemmas and tensions in their roles, how the reality of living with a person compares to their expectations, what kinds of support makes a positive difference to them. These discussions are best conducted by a board member or an outside resource person.
- Have a board member or an outside resource person interview each departing housemate to review what helped and what got in the way in their relationship with OCL.
- Carefully review what happens in situations where housemates are not active participants in the process of assisting people to make plans and take steps toward better futures.
- Carefully review what happens in situations where housemates do not take up opportunities to learn more about the practical implications of social role valorization for the person they live with.

### Making the most of the gifts and learning of all staff

Possible Problem Scenario

Growing enthusiasm for individualized supports and growing awareness of the limits of group residences polarizes OCL staff. Staff who work in group residences feel less valuable than staff who support people individually; staff who support people individually feel at least slightly superior to staff who work in group residences.

Admiration for the commitment demonstrated by OCL staff who voluntarily share their home life with people with disabilities not only creates a separation between staff who share their home lives and staff who do not, it also leads to the perception that those staff are above criticism for their job performance and that they don't need support to deal with the tensions and problems that arise on the job and at home.

Opportunities

- Set up problem solving and brainstorming sessions on individualized support issues and invite group home staff to participate as resource people.
- Set up problem solving and brainstorming sessions on group residence issues and invite individualized service workers to participate as resource people.
- Assure that group residence staff have opportunities to develop and use skills as facilitators of personal planning and group problem solving.

- Rigorously overcome the temptation to lower expectations for people who live in group residences. The problems of congregate living cannot become an excuse for avoiding ways to increase people's choice, community involvement, and engagement in valued social roles.

  *"There needs to be a collective understanding: there are no experts, but instead a group of people working together and figuring things out together."*

- Invite staff who also share their home life to identify and meet regularly with a board member or an experienced person outside OCL who will act as a sounding board and guide.
- Invite staff who also share their home life to brainstorm a variety of ways OCL can support them.

### Keeping individual planning and case management in context

Possible Problem Scenario

OCL's success in planning and helping people implement plans in its own services leads OCL to assume that it can contribute to change in Onondaga County services by expanding its case management activities. This is especially appealing because it allows OCL to expand its resource base without expanding past the limits it has set for expansion of residential supports. OCL case managers discover that many of the plans they make with people can't be implemented. This leads to a) pressure on OCL to increase the number of people it serves, which in turn could erode the quality of its services by frustrating case mangers when OCL says "no" to people to whom case managers feel committed; b) pressure on case managers to develop plans that are 'realistic' (i.e. can be implemented by existing services); and c) a dilution of OCL's focus on its mission: the mission is about actively assisting people to make positive changes in their lives, not about making plans that others lack the will or capacity to implement.

Opportunities

- Carefully review the lessons from the positive changes people have made with OCL's help in order to identify what kinds of service values and capacities are necessary in order to implement good plans.
- Identify the specific ways OCL case managers can influence the way agencies other than OCL provide services.
- With help from knowledgeable others, assess the capacity of other agencies to implement plans made with OCL case managers in ways that are consistent with OCL's mission. [This line of questioning does not assume that OCL is superior to other agencies; and it does not assume that no other agencies in Onondaga County share OCL's values and ability to act. The purpose of these questions is to be sure than OCL doesn't put too

much faith in individual planning as an agent for changing other organizations.]

### Making a distinctive contribution in employment support

Possible Problem Scenario

OCL's overall positive reputation, and the strong personal commitment of some supported employment staff in sharing their homelife with people OCL supports, keep the board and the supported living program staff from regularly and thoughtfully exploring the question "What is OCL doing in supported employment that other agencies could not do at least as well as OCL can?" This leads to missed opportunities to make the most of the OCL mission in supported employment.

Opportunities

- Invite all of the supported employment providers involved with people OCL supports to a retreat to identify the key issues in improving supported employment practice and to share strategies for making improvements.
- For presentation to other OCL staff and families, describe the work accomplishments of the people OCL supports and specifically identify the lessons supported employment staff have learned about assisting people to be successful on the job.
- Carefully review, with interested board members and outside resource people, each individual situation in which a person has lost multiple jobs or experienced substantial cuts in work time. Rigorously question the implications of these situations for the way OCL develops employer and co-worker commitment to a person's success, and for the kinds of instructional supports and adaptations OCL offers.
- Conduct a similar review of situations in which OCL staff continue a high level of on the job support over time.
- Assure that supported employment staff maintain a keen awareness of people's job interests and hold high expectations of themselves in developing jobs with a clear link to these interests.

### Keeping the OCL mission alive

*"We need to keep thinking of ways to revitalize our energy, our spark: not just to live off the spark, but to brighten it."*

Possible Problem Scenario

Encouraged by growing external recognition of what people have accomplished with OCL's assistance, aware of a positive contrast between OCL's approach and that of many other agencies in New York State, OCL staff come to assume that they know how to live out the OCL mission, if only funders

and regulators will let them. This external focus distracts from opportunities to understand the implications of the OCL mission more deeply.

Opportunities

- At least once a year, convene a group of interested board members, family members, people assisted, staff, and supporters to answer this question: "How many different things will we do this year to keep our sense of mission alive and to deepen our understanding of what it means?" Possibilities include communicating the meaning of OCL's mission through...

  ...art work and photographs

  ...poems and stories

  ...music and drama

  ...personal and group reflection on different sections of the mission through writing and discussion

  ...celebration of small accomplishments

  ...careful documentation of ways of working that exemplify the spirit of the OCL mission

- Create exchanges with people with disabilities, families, and staff nearby who are doing similar work to counteract the tendency to believe that "we are they only ones who are this far along". Build up regular contacts among people from agencies with similar commitments outside New York State (e.g. in Rhode Island, Eastern Ontario, and Kentucky).

- Recognize that one danger of pioneering a new way of serving people is the creation of unspoken rules that make certain topics "undiscussable" and ...

  ...Create regular occasions when people can talk about uncertainties, doubts, and not knowing what to do. On these occasions, the focus would be better understanding of OCL's work, not on immediate reassurance or advice. Outside facilitation of these discussions may be helpful.

  ...Explore different ways to surface important issues; e.g. ask groups of staff to develop visual metaphors for OCL: "If OCL were a vehicle, draw what would it look like."

  ...Create times to explore dilemmas in OCL's work such as the balance between respecting people's choices and encouraging them to work for important changes in their lives.

  ...Reflect on and work to change whatever keeps staff from saying, "I need help." "I am worried about..." "Here is how you could support me." "Here is exactly what I want or need." "I don't know."